



Research Paper

Still Alice and Beyond: Chronic Illness and the Crisis of Identity

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ABSTRACT: Living with a chronic medical condition is not merely an interruption to one's life; it fundamentally alters self-perception and how others perceive the individual. It is not just a biographical disruption but also a profound psychological, emotional, and existential upheaval. Enduring a chronic illness demands resilience and determination, as individuals grapple with loss, redefine their identity, and navigate an altered existence. This paper delves into the complex identity crisis experienced by individuals confronting chronic illness, drawing insights from Lisa Genova's novel, "Still Alice." Through the lens of Alzheimer's Disease, it explores the disintegration of identity, the fragmentation of selfhood, and the existential void that ensues. The narrative examines not only the physical and psychological toll but also the shifting dynamics within families, and society's response to the suffering individual. The paper also explores the intersection of gender with illness. Ultimately, it contemplates the metamorphosis of identity in the face of relentless suffering, offering a nuanced exploration of Alzheimer's profound impact on personal, social, and existential levels.

KEYWORDS: Identity- crisis, biographical disruption, existential crisis, deterritorialized, suffering, memory, Alzheimer's disease.

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I. INTRODUCTION

Navigating the terrain of chronic illness reveals a complex path that goes far beyond physical suffering. Following the pandemic, many people have found themselves on a familiar journey. Chronic illness goes beyond mere bodily disturbance; it seeps into the fundamental fabric of one's being, eroding emotional resiliency, psychological fortitude, and existential meaning [1]. People's sociocultural perspective drastically shifts, mirroring the transformed self-perception that accompanies chronic medical conditions. Living under such circumstances necessitates a complex dance of negotiation and sense-making as people struggle with the stark truth of their new identity. People frequently use nostalgia for a bygone era of robust health as an emotional backdrop, juxtaposing it with the harsh realities of worsening health, treatment side effects, and a newfound permanence in an altered self-image [2].

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.¹

It is like traveling to a parallel universe, one marked by shadows of uncertainty and emotional desolation—a place where familiarity transforms into frightening strangeness, forever changing the landscape of one's reality [3]. Temporal distortions intensify the labyrinthine character of chronic illness as the pace of daily living slows to satisfy medical needs. The rhythm of time becomes a volatile force, alternating between quick progression and agonizing standstill, trapping individuals in a transitional state where clock time loses its hold [2]. The narrative arc of Lisa Genova's "Still Alice," which dives into the grim realities of early-onset Alzheimer's disease, is a moving examination of the complexities of chronic illness [4]. It invites us to look beyond the

¹ Sontag, S., *Illness as Metaphor*, 1978, p. 1.

bounds of tragedy and to delve further into how chronic sickness not only removes layers of identity and self-worth but also plunges people into the abyss of existential nothingness. Identity arises as a contested territory, defined by the many roles people play throughout their lives—child, parent, friend, husband, scholar, and so on. Illness can ruthlessly tear away these layers, leaving behind the stark visage of "Still Alice"—a frightening reminder of the dramatic alteration illness causes.

II. STORYING ALZHEIMER'S: LISA GENOVA²

Still Alice [4] intricately weaves the poignant narrative of Alice Howland, a fifty-year-old woman deeply entrenched in her personal and professional life. As a stalwart figure in academia, Alice's twenty-five-year tenure as a psycholinguistics professor at Harvard University underscores her passion for language sciences and her dedication to teaching. Revered as a distinguished speaker in psychology circles worldwide, Alice's fervor for her field knows no bounds. However, the onset of early Alzheimer's disease disrupts Alice's seemingly idyllic existence, unraveling the fabric of her family and professional dynamics. Caught in the throes of cognitive decline, Alice grapples with the loss of control over her body, her once-sharp intellect, and her cherished role as an educator. Each memory lapse serves as a poignant reminder of her impending descent into the abyss of forgetfulness, where the very essence of her being hangs in the balance. Divided into sections titled after the seasons and months, the novel's temporal framework—spanning from September 2003 to September 2005—imbues the narrative with a sense of inevitability akin to the passing of time and changing seasons. The recurring motif of dysfunctional clocks in Alice's home serves as a poignant metaphor for the irreversible nature of her condition, further emphasizing the inexorable march of time [2]. Embedded within the temporal structure are poignant recollections of Alice's past, intricately woven into the fabric of her present. These memories serve as a testament to the significance of memory in shaping one's identity, underscoring the profound impact of Alzheimer's on the very essence of selfhood [5]. As Alice navigates the labyrinth of her diminishing memories, the novel explores the intricate interplay between memory, sensory perception, and identity, highlighting the intrinsic link between one's ability to remember and one's capacity to truly live [4].

III. A GLIMPSE OF NORMALCY: ROUTINE PRIOR TO ALZHEIMER'S

Alice and her husband used to embark on their daily ritual of walking to Harvard Yard, a mere mile from their home, together. Each day, without fail, they paused at Jerri's spot for a refreshing pause: a cup of lemon-infused tea for Alice and a strong black coffee for John. These moments of shared tranquility were cherished by Alice, serving as a prelude to the bustling day ahead. Their journey through Harvard Square was not just a physical exercise but a mental one too, a time for deep conversations about their academic pursuits, their children, and the plans awaiting them in the evening. Alice found solace in the rhythm of their jog, finding inspiration and connection in the exchange of ideas with her husband. Alice was a creature of habit, meticulously organizing her days with a digital "To Do List" that served as a blueprint for her daily routines. Her commitment to her classes was unwavering, and she took great joy in being a supportive presence for her students. Engaging in academic seminars and sharing her knowledge through published papers and books brought her immense fulfillment. Reading was not just a hobby for Alice; it was a passion, a gateway to new perspectives and ideas. Her dedication to her profession was evident in her meticulous attention to detail and her insistence on perfection. Alice's love for her work transcended mere occupation; it was a calling she pursued with unwavering dedication and an unyielding quest for excellence. The following passage exudes a serene and contemplative tone. The author's portrayal of Alice enjoying the "relaxed intimacy" of the morning walks implies a feeling of tranquility and satisfaction. Moreover, the text evokes a reflective mood by juxtaposing the serenity of the walks with the strain and weariness of daily obligations, seemingly encouraging readers to contemplate the fleeting moments of peace amidst the chaos of life. The author employs vivid and detailed language to depict the morning walks, enabling readers to mentally perceive the setting and experience the ambiance of serene closeness. The author likens the morning walks to a period of "serene closeness," suggesting that they cultivate a tranquil and intimate bond between Alice and her strolling companion. The reference to "the daily demands of their jobs and ambitions" suggests possible conflicts or obstacles that Alice and John encountered later in the story, enhancing the complexity of the narrative. The author provides insights into Alice's character and relationships by highlighting her delight in morning walks and contrasting it with her feelings of worry and tiredness throughout the rest of the day.

² Lisa Genova, born on November 22, 1970, is an American neuroscientist and acclaimed author. She graduated with top honors from Bates College, earning a degree in Biopsychology, and later obtained her Ph.D. in Neuroscience from Harvard University in 1998. Genova is renowned for her bestselling novels, including "Still Alice," "Left Neglected," "Love Anthony," and "Inside the O'Brien's," as well as the nonfiction work "Remember: The Science of Memory and the Art of Forgetting" (2021). Her writing delves into the perspectives of characters facing neurological challenges, reflecting her background in neuroscience.

Alice savored the relaxed intimacy of these morning walks with him before the daily demands of their jobs and ambitions rendered them each stressed and exhausted.³

IV. INITIAL EXPERIENCE OF ALZHEIMER'S: LOST IN DENIAL

While delivering a lecture on the mechanism of language at the University of Stanford, she forgot a specific word in a sentence that humiliated her from within in front of audience, as she has never lost a word in her twenty-five years career. She managed to replace the word (thing).

"The data reveal that irregular verbs require access to the mental...(lexicon)....."⁴

She repudiated it by justifying it as the effect of champagne she had at the party before the event or jet lag. She attributed her lack of focus to menopause or multitasking or excessive travelling. Alice forgot her mobile phone in a restaurant at Los Angeles, where she dined with Lydia; the waitress returned the phone to her. She was inexplicably lost within a mile distance from her home after a jog; stood on the intersection of streets, missing out the context of where she was and what would be the street to her home. The familiar landscape gets defamiliarizes⁵ for a while [6]. She again tried to look away from this lapse as due to over running, anxiety, and perspiration. She started becoming unreasonably needy most of the time, arguing, bickering over trivial matters, anxious, scared, & wanted to be at home (safe space).

Alice is trying to remain in the denial mode⁶ as she knows that something is wrong with her memory [7], and it is established on the very first page of the novel. While looking for the John's glasses, Alice contemplation is well-reflected in the following passage that alluded to a theme about perception and cognition. Alice's observation about her husband's oversight raises questions about how we perceive and process information, particularly when dealing with familiar objects or routines. Memory loss and cognitive decline are central themes in the novel. The description of the granite countertop's smooth, uncluttered surface and the heaping mushroom bowl of unopened mail paints a vivid picture of the scene, emphasizing the contrast between the clean space and the clutter. The irony is that John is described as "well, so smart, a scientist," despite his inability to see the glasses right in front of him. This irony emphasizes the gap between intelligence and perception. The use of phrases like "not under something, not behind something, not obstructed in any way from plain view" emphasizes the obviousness of the glasses' placement and reinforces Alice's skepticism. The author characterizes Alice's frustration and possibly growing concern about cognitive issues through her internal thoughts, laying the groundwork for further exploration of these themes later in the novel.

She looked across the smooth, uncluttered surface of the granite countertop, and there they were (glasses), next to the mushroom bowl heaping with unopened mail. Not under something, not behind something, not obstructed in any way from plain view. How could he, someone well so smart, a scientist, not see what was right in front of him? Of course, many of her own things had taken to hiding in mischievous little places.⁷

V. GENDER UNDERPINNINGS

The novel is narrated from Alice's perspective, offering readers an intimate glimpse into her thoughts, emotions, and experiences as she navigates life with early onset of Alzheimer's disease. By making this narrative choice, Genova delves into the impact of the illness on Alice's identity as a woman, mother, and wife [8]. In Genova's portrayal, the impact of Alzheimer's is not limited to Alice alone but extends to her entire family, including her husband and three adult children. The gender roles within the family are being explored as John, her husband, assumes a caregiver role traditionally associated with women [9]. The shift in gender roles that is occurring challenges the norms and expectations of society. Alice is a highly accomplished linguistics professor, and her career holds great significance in shaping her identity. As the disease continues to advance, she struggles with the decline of her intellectual capabilities and the loss of her professional accomplishments [10]. Genova delves into the impact of gender expectations and societal pressures on a woman's self-worth and identity,

³ Genova, L., *Still Alice*, 2007, p. 7.

⁴ *Ibid.*, p. 11.

⁵ Defamiliarization, coined by Russian formalist, Victor Shklovsky, a common occurrence in literature and other forms of art and media, can be seen in several techniques, such as framing. Defamiliarization, or "ostranenie" in Russian, involves presenting familiar things that seems unfamiliar or strange to provoke new ways of seeing and thinking about them. Russian formalism and literary modernism often discuss this concept, which has significantly influenced literary theory.

⁶ Denial Mode is the first stage of the Five stages of grief as proposed by Kubler- Ross, in which the person affected by a loss, or a sense of loss prefers to remain in the denial mode.

⁷ Genova, L., *Still Alice*, 2007, p. 4.

specifically when faced with a debilitating illness. In the following passage, gender intersects with illness in the context of professional career obstacles and Alice's altered perceptions about herself during her illness that makes her contemplate about her past [11]. Alice discusses her own problems as a woman with three children, including the physical toll of pregnancies and childcare responsibilities, which have hampered her ability to grow in her job as a linguistics professor. Alice describes her professional journey as a *daunting task*, a metaphor for the problems and obstacles she experiences in her career. The author uses imagery like *side effects of three pregnancies, anaemia, preeclampsia, and endless lullabies* to vividly depict Alice's struggles with illness and motherhood in order to convey the physical and emotional toll of her experiences. The repetition of sounds, like in *anaemia, preeclampsia, and endless lullabies*, produces a rhythmic effect and highlights Alice's insurmountable obstacles. Alice's comparison to John represents greater cultural inequities between men and women in academic and professional domain. Her thoughts underscore the additional costs and barriers that women endure as a result of gender standards and caregiving responsibilities [9]. Alice's question on whether John's research career would have withstood similar health issues has an ironic twist. This irony highlights the unequal expectations and standards that women face compared to their male counterparts.

Alice compared her professional career with John; full time professorship tenure had been a daunting task for her, not just because she did not produce an outstanding body of work in linguistics or the task was too hectic for her but it's just that she is a woman with three children; the side effects of three pregnancies, anaemia, preeclampsia, and endless lullabies, only two or three hours of uninterrupted sleep never ending demand of the kids, certainly distracted and slowed her down; she wondered whether John's research career would have survived such health hiccups.⁸ (Alice Howland)

The subsequent passage is a poignant reflection of Alice Howland. The word "smacked" conjures up a visceral image of Alice's emotional response to the word "needy." It implies a sudden, strong reaction that strikes her like a physical blow. Alice's association of the word "needy" with negative traits like weakness, dependence, and pathology is a metaphor for her relationship with her father. It emphasizes her fear and determination to not resemble him in any way. The author portrays Alice's complex emotions and past experiences with her father through her internal reflections. This sheds light on Alice's personality and motivations, enhancing the reader's understanding of her character. The conversation itself is used as a literary device to reveal tension and conflict between John and Alice. John's use of the word "needy" and Alice's reaction to it reveal underlying issues in their relationship, as well as Alice's inner struggles. Alice's reference to her father⁹, as well as her lifelong effort to avoid resembling him, alludes to her personal history and family dynamics. This adds depth to the story by contextualizing Alice's emotions and actions. The passage's tone conveys Alice's emotional vulnerability and internal conflict. She is deeply affected by John's use of the word "needy," which brings up painful memories and insecurities about her relationship with her father. There is a sense of distress and introspection as Alice struggles with these emotions and her desire to distance herself from any resemblance to her father. The passage contains a motif of identity and self-perception [2]. Alice's reaction to being labeled as "needy" reflects her ongoing struggle to define herself and assert her independence, especially considering her father's perceived weaknesses. This identity motif runs throughout the novel, as Alice deals with the changes brought on by her early-onset Alzheimer's disease diagnosis and struggles to maintain her sense of self in the face of cognitive decline.

You need to talk now, you need to be home, you are awfully needy all of a sudden. Is something else going on? (John) The word needy smacked the vulnerable nerve in her. Needy means weak, dependable, and pathological. Her father. She had made a life-long point of never being like that, like him.¹⁰

Alice attempted some deep breathing exercises to calm her nerves. She could not tell anyone about her condition as she could not understand it, could not be able to make sense of what was happening around her at that point in time. She did not want to show her emotional, vulnerable side even to her husband; she tried to assemble herself a bit and then her train of thought ran back when she forgot that specific word during the lecture at Stanford and other current memory lapses. This narrative highlights the significance of acknowledging and tackling gender bias in medical discussions, especially concerning women's health topics like menopause [12]. The passage emphasizes the importance of healthcare providers taking a holistic approach while treating patients, considering various factors and potential diagnoses instead of relying on gender stereotypes and assumptions [10]. The phrases like *nothing life-threatening* and *nothing abnormal* suggest the naturalization of menopause discourse that prevented Alice to think beyond that and to consider other potential pathologies related to her frail memory and

⁸ Genova, L., *Still Alice*, 2007, p. 35.

⁹ Alice inherited Alzheimer's disease from her father as reflected through her investigations. She hated her father throughout her life as she holds him responsible for the fateful accident in which her younger sister and mother died due to her father's reckless driving. He used to drink because he did not make sense of what was happening with him due to his undiagnosed Alzheimer.

¹⁰ Genova, L., *Still Alice*, 2007, p. 27.

disorientation. The author employs evocative images to convey menopausal symptoms like hot flashes, night sweats and insomnia. This imagery helps the reader visualize and empathize with Alice's situation. Menopause symbolizes aging and the passage of time. It signifies a big life transition for Alice, ushering in a new chapter in her life. The recurrence of the word "check" highlights Alice's understanding and self-assurance of her symptoms, as well as the implied irony that Alice is already aware that something is wrong with her and has been searching for a comforting solution to the root cause of her frail memory. The use of the word "check" implies that the symptoms are commonly associated with women's menopause, highlighting the irony that not every human body is the same. The recurrence also emphasizes the metanarrative aspect of menopause conversation, which is naturalized and concealed by an act of repetition. It supports the perception that these sensations are frequent among menopausal women. The section provides insight into Alice's thoughts and inner monologue as she considers her symptoms and looks up information online. This narrative style provides insight into Alice's mental and emotional state.

She thought about the missing word during her talk at Stanford and her missing period, she got up, turned on her laptop, and googled "menopause symptom." An appalling list filled the screen ... hot flashes, night sweats, insomnia, crashing fatigue, anxiety, dizziness, irregular heartbeat, depression, irritability, mood swings, disorientation, mental confusion, memory lapses. Check, check, and check. This was just the natural, next phase in her life as a woman. Millions of women coped with it every day. Nothing life-threatening. Nothing abnormal.¹¹ (Alice Howland)

She attributed it to her missing periods, googled about menopause and its impact on the women's health that includes irritability, hot flashes, insomnia, mood swings, memory lapses, disorientation, and mental confusion. She prefers to remain in the denial mode [7]. In the novel, Alice's explanation of her memory lapses as a result of menopause highlights the way society frequently interprets women's health experiences in a gender-specific manner. Menopause is a natural biological process that every woman experiences, but it is frequently portrayed in a negative or medicalized way [13]. Women frequently encounter a continuous stream of information and actively participate in conversations around menopause, both through various media outlets and from healthcare practitioners. Occasionally, this exposure can lead individuals to link different symptoms with this specific phase of life. Occasionally, the emphasis on gender can mask other significant health issues [14]. Alice has failed to consider alternative explanations for her memory lapses, potentially because of the preconception that women encounter forgetfulness or emotional instability after menopause. This stigma can lead healthcare practitioners and women to disregard or underestimate other health issues, such as Alzheimer's disease, which Alice eventually develops.

VI. Subjective & Intimate Experience of Alzheimer's Disease

Sensory Perception Heightened: Alice suddenly started feeling & listening to the silence of the house, the strange & distant sounds like neighbor's barbecues, smell of grilling ham burgers. She could not connect in one of the items in her "to do list" that only read "Eric" - Eric Wellman is the head of psychology department at Harvard, but she could not connect any task related to Eric. She threw the reminder list fourth time that day into the trash and pulled off a new one. Eric? The following line conveys Alice's memory disturbances as disruptive and distressing. The memory disturbances are portrayed as "rearing their ugly little heads," giving them agency and making them appear almost alive or sentient. This personification highlights the disruptive and unwelcome nature of these disturbances. The phrase "rearing their ugly little heads" is a metaphor for the sudden onset or recurrence of memory disturbances. It implies that these disturbances are unpleasant and undesirable, analogizing them to unsightly creatures or problems that disturb Alice's peace of mind. The word "ruffled" paints a vivid picture of Alice's emotional state, implying agitation, disturbance, or disarray caused by the frequent occurrence of memory disruptions. This imagery conveys Alice's intense reaction to these disturbances, emphasizing their impact on her well-being.

Memory disturbances like these were rearing their ugly little heads with a frequency that ruffled her.¹²

Alice found herself offering reassurances repeatedly, a mantra to quell the rising tide of anxiety: "Everyone forgets, everyone grows tired, everyone feels stressed." Yet, the incident in her classroom shook her to the core. Despite meticulously preparing for her lecture just an hour prior, the topic slipped from her grasp, leaving her disoriented and deeply unsettled. Even as she opened her computer to access her lecture materials, the contents of her own lesson plan eluded her, lost in the labyrinth of her faltering memory. The realization of her cognitive lapses struck with startling clarity when she received an email from Eric Greenberg, a colleague from Princeton, requesting slides for a presentation—a task that had completely slipped her mind. Names blurred together, distinctions fading into a haze of confusion. Even the most basic obligations, like catching her flight to Chicago for a seminar, slipped through the sieve of her consciousness, despite being meticulously noted in her planner. She

¹¹ Genova, L. *Still Alice*, 2007, pp. 28–29.

¹² Genova, L., *Still Alice*, 2007, p. 33.

failed to recognize Beth, the wife of one of her students, despite spending an hour in her company. The gravity of her forgetfulness was lost on her; a lack of awareness cast a veil over the gaping holes in her memory. Moments of solace were fleeting, found in the pages of old family albums that whispered tales of yesteryears. But these relics of the past only served to underscore the erosion of her present faculties, casting a shadow over the uncertain expanse of her future. The specter of her looming diagnosis loomed large; a monstrous entity poised to envelop her in its suffocative embrace.

VII. COPING MECHANISM

Alice tried to cope with the precarious situation by indulging herself in various activities that could help in stimulating her dying neurons [7]. She decided to rehearse, and to practice, to do some brain exercises to stimulate neurons. So, she opened a dictionary page randomly and selected a word from the page then wrote it on a piece of paper and then after an interval of forty minutes tried to remember that specific word. She succeeded in her initial training games. But she struggled to memorize the words in between listening or attending to other voices. She must concentrate on hearing her own inner voice, the one repeating the same words to memorize.

She did well in all her cognitive domain, but she had a recent memory impairment that has been interfering in her professional as well as personal life; and she was clinically diagnosed with *Probable Alzheimer's Disease*- the word probable gave her some life, some air to breathe as she might not had it. But doctors told her that probable meant that Alzheimer can be diagnosed only by examining the histology of the brain tissue. Brain atrophy can only be seen in Magnetic Resonance Imaging (MRI) at the later stages.

VIII. LIQUIDATION OF IDENTITY

The following passage delves into the issue of identity loss and trauma within the framework of a catastrophic medical diagnosis. Alice's experience of feeling fragmented, disassociated, and divorced from herself exemplifies the significant influence that chronic disease may exert on an individual's sense of identity and selfhood [2]. The author depicts Alice's emotional condition as profoundly saddened and detached from her surroundings. The reference to feeling as if her molecules are dispersed and observing herself from a distance underscores the intense astonishment and detachment she undergoes upon learning of her diagnosis. The use of imagery vividly portrays Alice's emotional and psychological agony, depicting the penetrating sound of her name resonating within every cell and the sensation of dispersing beyond the confines of her own skin. These images elicit a feeling of disintegration and a lack of personal identity. Alice emphasizes her disconnection from her physical form and the world around her through her metaphor of envisioning herself as an ethereal entity and hearing her own voice from afar. This metaphor emphasizes the deep sense of confusion and isolation she experiences when confronted with her diagnosis; it also suggests an out of body experience. The author utilizes the phrases "hollow utterances" and "empty gaze" to express the profound sense of emptiness and emotional numbness that characterize Alice's state of mind. The descriptions highlight the deep feeling of hopelessness and existential misery she feels after receiving her diagnosis. The lines are the poignant reflection on the territorial quality of trauma; it deterritorialized a subject. She developed into a well-known example of the destructive plasticity, in which trauma results in the loss of one's identity and the construction of a new identity that is unrelated to the older one, entirely erasing the subject's memories and history. The experience of suffering facilitates the development of a lasting identity [15]. The subject experiences a disruption in her perception of time and space, leading to a state of disorientation. The process of transforming the subject in a nihilistic manner can be considered a state of *traumatic metamorphosis* [15]. Nevertheless, attaining such disengagement during a traumatic incident or in the aftermath of trauma may present difficulties. Individuals who are managing an illness or disability undergo a state of suffering that persists as a continuous process. Viewing trauma solely as a medical condition would involve adopting a reductionist viewpoint, which is inadequate for achieving a thorough comprehension of the phenomenon. There are two distinct types of traumatic cognition: the first is a deeply ingrained, unique, micro-level occurrence that is distinguishable by neural, visceral, and psychological expressions. The second category is characterized by its external nature and relates to the encounter with estrangement and seclusion from an individual's societal milieu [15].

Alice was devastated as if something had bombarded her, the sound of her name uttered by the doctor penetrated every cell and seemed to scatter her molecules beyond the boundaries of her own skin. She watched herself from the far corner of the room like an ethereal presence. Her voice seemed to be coming from a distance, hollow utterances, empty gaze, no hope, a feeling of nothingness enveloped all over her. She heard her voice asking what did that mean? The words and their meaning seemed to float in the air above her head, she imagined herself out of her body and trying to catch the words with the correct meaning.¹³

Unfortunately, Alice belonged to the category of 10% people who have early onset of Alzheimer disease. Usually, 90 % of elderly people are susceptible to this disease. The early onset of this disease has a strong genetic

¹³ Genova, L., *Still Alice*, 2007, p. 79.

linkage. She searched her doctor's face for some hope but the only thing she noticed was truth and regret. The doctor's insistence that she must bring somebody with her as the information provided by her cannot be considered reliable had hit Alice badly. The Daily Living Questionnaire handed over by Dr. Davis to her was in her hands and it should be supposed to be filled in by the informant not by the patient. The rating scale of each activity ranged from 0 to 3 (normal, same as ever, severely impaired). She scanned down the description of no. 3 ratings i.e., the end stage of the disease. She felt that she was forced into a car on a straight and short road without brakes and steering. She felt powerless. Number 3 was humiliating list that included: totally dependent on other for food, no control over bowel and bladder, could not handle money matters, could not work for long hours, needs assistance in cleaning and grooming, medication given by others, home and hospital bound.

IX. ANNIHILATION OF AGENCY

The worst of it was under the heading "Communication"- in the final stages of Alzheimer the speech becomes almost unintelligible, could not understand what people say, given up reading, no writing. *No More Language*, the thought of living without language scared her to her core, she looked at all the research articles, published books, and papers on her book shelves, the books which she always would love to read one day when she would have time (*Moby Dick*). Everything she did, she is, and she achieved required 'language.' She wanted to do something for herself, wanted to try; maybe her case would be different as she was too young and smart. 'John loved her brain so much, her independence; how could he love her like that?' This fear is deeply rooted in the stigma associated with behavioural or psychological disorders and that is why many individuals are uncomfortable talking openly about their medical conditions [16].

X. IMPACT ON SOCIAL INTERACTIONS

Alzheimer's disease deeply affects Alice in all domain of her life. She feels that everything has slipped away from her hand like a powder of sand. Alice could not grasp the conversation on the phone correctly, so could not be able to respond quickly. She needed the aid of the visual cue of the person; otherwise, telephonic conversations baffled her, her comprehension suffered. She could not travel alone. She could not attempt an activity with the fear of losing her cognitive control over herself and facing her own decline of her rational faculties. She tucked a piece of paper with her address, name, phone no. written on it in her socks just as a precautionary measure; but how come if she forgot that she contained a piece of information with her? Later she registered with Alzheimer's Safe Return Programme. Alice became totally dependent on her Blackberry phone, which she used to keep in the small blue string bag given to her by Anna. She holds the butterfly¹⁴ necklace very close to her inherited by her mother. Holding that piece of jewelry provides her with a sense of familiarization. Alice finds solace in the memories of her past, keeps them close to her heart like some precious treasure; the nostalgia for the past is often observed in the ill people, they always aspire to go back to their healthy past [11].

XI. FAMILY DYNAMICS: COMMUNICATION BREAKS DOWN

John stopped asking for her help with mundane things like looking for her trousers, glasses, and papers. John could not stand Alice taking medication for the disease. He left immediately as soon as she started popping her pills. Her family openly discussed her condition in front of her and made decisions on her part without even including her considering her as unfit for the conversation. Catherine Malabou in her seminal work *New Wounded: From Brain to Neurosis* talks about Alzheimer's disease as the classic trope of *Destructive Plasticity*¹⁵ that she considers it as neural phenomenon. She offers a new definition of mental wound/ mental injury. According to Malabou, human brain consists of synaptic gaps through which the information process and transferred and, the more synaptic our brain is the more plastic it becomes and during any trauma or a disease like Alzheimer's Disease causes explosion inside the brain and there is no way the brain can detour the excessive energy and that impacts brain negatively [15].

Destructive plasticity is spectacularly rampant in Alzheimer's disease. What patients of Early Onset of Alzheimer's Disease show us the plasticity of the wound through which the permanent dislocation of one identity forms another identity; that is neither the sublation nor the compensatory replica of the old form, but literally a

¹⁴ Alice's childhood memory is connected to butterflies that symbolizes short and beautiful lives; whom she admired a lot and when her teacher told her that butterflies have a short life span, she cried and asked her mother, her mother consoled her that it's just not the duration that matters but the quality of life a person lives is more significant and these colorful creatures spread happiness for others.

¹⁵ Destructive Plasticity refers to the brain's capacity to endure detrimental alterations or harm in reaction to traumatic experiences or neurological insults.

form of destruction. It proves that destruction is a form that creates a new form, and that form is an interrupted identity, a interrupted self both medically and existentially, a broken subjectivity; destroys the memory and history of the subject.¹⁶

XII. NAVIGATING THE DARKNESS

She thought of spending more time with her family assisting John, helping Anna in her writings, advising Lydia's acting skills, but she also thought that each of her children have 50% chance of having Alzheimer and when it was revealed they would hate her as she hated her father throughout her life for being disoriented and dependent. Alice wanted to find solace in the God almighty, visited church but could not find peace of her mind and answers to the questions that did not let her sleep for so long. They came crumbling over like an avalanche or a bunch of black pythons strangulating her, sometimes like indistinct shadows flickering between light and dark, but could not get a relief and answers of the inevitabilities overshadowing her present and her future. She wanted to hold a serious conversation with John about her future inconsistencies and to tackle it with long term plan. But John was too shattered to even talk about it, leave aside consoling her or providing her moral support.

They were both a year away from taking sabbatical once more as they both took it six years ago while working on a book "From Molecules to Mind". So, they decided to tell their children about it and nobody else, and that she would avoid travelling.¹⁷

She told her children about her illness during the Easter holiday; they all reacted practically and differently to the situation, Anna the eldest daughter was apprehensive as she was trying to conceive through intra vitro fertility (IVF). Alice genes could be transferred to any of them, so they all got genetically screened and surprisingly Tom's result was negative, while Anna had the mutation with PS1. Lydia did not opt for the test. Anna had also tested embryo mutation for her future kids; and it was found out that the mutations in the embryo can be avoided through a procedure. Alice felt jealous of Anna that she had the chance to save the future of her children from the disease.

XIII. MANAGING ALZHEIMER'S ALONE

Alice visited Alzheimer Special Care Unit, where she found out that mostly elderly people had Alzheimer and they were all confined in a space, indulged in various activities, they did not converse, did not communicate, did not have emotions and no one visited them not their family members. They all seemed lost in that confined space alienated and lonelier away from their loved ones. Alice deleted this option for her future. And it will cost her \$280 a day. She did not want to be an emotional and financial burden on a man to whom she would forget one day as evident in the following lines from the novel.

She needed a better plan, one that did not include her playing beanbag toss with Evelyn in the Alzheimer's Special Care Unit. One that did not cost John a fortune to keep alive and safe a woman who no longer recognized him and who, in the most important ways, he did not recognize either.¹⁸

Alice's demeanor is marked by a persistent apprehension, a palpable urgency in confronting the stark realities of her uncertain future. The looming specter of becoming a burden on her family weighs heavily on her mind, as does the profound fear of gradually fading into the abyss of oblivion, forgotten by those she holds dear. This apprehension is deeply rooted in the pervasive stigma that surrounds mental disorders, particularly dementia, within our culture. The onset of Alzheimer's disease not only encroaches upon the individual, silencing their voice and isolating their experience, but it also casts a shadow over the lives of their family members. The degenerative nature of the disease inflicts a profound toll, leaving loved ones grappling with a sense of helplessness in the face of its relentless progression. They bear witness to the gradual erosion of their loved one's psyche, navigating the labyrinth of a fractured mind and fragmented identity with a profound sense of bewilderment and sorrow [17].

Alice wished she had cancer instead of Alzheimer's, longing for the battles of chemotherapy and radiation where support from her family and the Harvard community would rally behind her. In an epiphany moment, she contemplated suicide, leaving instructions for herself on her computer. Despite her attempts, she could not bring herself to execute the plan. Her cognitive decline over the past six months severely impacted her abilities, leading to disorientation in time and space, insomnia, and blurred lines between past and present. Her multitasking skills dwindled, and conversations became challenging as her mind struggled to grasp meaning. Her illness progressed rapidly, leaving her grappling with the effects of amyloid buildup on her mental faculties.

¹⁶ Malabou, C., *The New Wounded: From Neurosis to Brain Damage*, 2012, p.

¹⁷ Genova, L., *Still Alice*, 2007, p. 113.

¹⁸ Genova, L., *Still Alice*, 2007, p. 129.

XIV. SHARED REFLECTIONS: VOICE OF CONCERN

Lydia¹⁹ seeks to engage her mother as she is now and turns towards art and relationships. She used her art and emotions to connect with her lost mother [18]. The author explores that art-focused efforts improve the lives of people having Dementia and calls these efforts "Moral experiments", drawing on the on-going interview-based research in which care givers employ art and emotions to connect with the Alzheimer's patient. Lydia endeavors to authentically connect with her mother by engaging in heartfelt conversations, making direct eye contact, and delving into her emotions to understand her struggles. Through this empathetic approach, Lydia attempts to penetrate the internal world of dementia, ultimately providing her mother with unparalleled support. While Lydia may not fully grasp the complexities of dementia, her efforts prove invaluable in aiding her mother's journey. Alice, in turn, shares with Lydia the various phases she encounters multiple times daily, further enriching their bond and Lydia's understanding of her mother's condition [4].

I know what I am looking for; my brain just cannot get to it. It was like if you decided you wanted that glass of water, only your hand would not pick it up. You ask it nicely, you threaten it, but it just does not budge. You might finally get it to move, but then you grab a saltshaker instead, or you knock the glass and spill the water all over the table. Sometimes the moment of need has passed in this struggle. You do not need water anymore. It was like third-degree torture. You know it and you cannot do anything to stop it, because your free will, agency, control is not available to you.²⁰

Lydia characterizes Alice's ability to perceive non-verbal signs and unexpressed emotions as a valuable quality for an actress, highlighting the similarities between Alice's skills and the demands placed on performers. This metaphorical analogy elucidates Alice's innate ability to comprehend the emotions and behaviors of others by drawing a parallel to a skill employed in a distinct domain. The term "actor" refers to the realm of theater and live performances. The text suggests that performers must detach themselves from verbal communication in order to authentically respond to others' feelings, emphasizing the need for empathy and emotional genuineness. This enhances the portrayal of Alice's perceptiveness.

Alice was more sensitive to what was not said, to body language, and unspoken feelings. Lydia explained this ability as an asset to an actor where an actor has to divorce from the verbal language in order to be honestly affected by other's actors feeling and actions.²¹

During an epiphany moment at Harvard Square, she bought a chocolate ice cream with pea nut and enjoyed the creaminess of it. Her goals had suddenly diverted from being a professor at Harvard, writing papers, publishing books to enjoying the present moment in her life like enjoying the little pleasures of life, which she had been neglecting for so long. Virginia Woolf's "On Being Ill" explores that Illness is the portal of self-understanding, and self-actualization [19]. The person become more closer to our selves during an illness, truer to ourselves.

At the fall after the summer at Harvard (September 2004), she was called by Eric Wellman (HOD) head of the department and questioned for the student's evaluations and their written remarks about her teaching skills. Few students also contested the grades given by Alice and that never happened in her 25 years of career.

"I can't live with a reputation of being a depressed, stressed-out addict. Having dementia has to carry less of a stigma than that."²²

She broke the news to Eric about her disease and despite his profoundly empathetic attitude shown by him, he had to fulfill the responsibility of being a head of the department (HOD). So, the teaching classes, research activities, attending conferences at the other universities were all taken away from her with the utmost politeness and gratitude. She was asked to apply for medical leave with immediate effect and then can go to sabbatical after Christmas. Eric just wanted her out of the Harvard at any cost; as she had become a misfit in the place. She wrote a general mail addressing all her colleagues and students about her illness and informing her that she would willingly give up her teaching, research, seminars as it would not be possible for her to continue like that. She would only work as Dan Maloney's thesis advisor and will try to actively participate in meetings and seminars held at Harvard. They all felt so sorry for her and as fast as they took away the ascribed charges and duties; they immediately left her alone. Those meaningless apologies, synthetic & sterile gazes, formal utterances, hugs without warmth, hollowed Alice inside out. Facing her meant facing her mental frailty and they wanted to avoid her at any cost; as it could happen to them too. Alice noticed that nobody sat next to her at a student's presentation although there was no availability of seats but people preferred to stand rather than sitting beside her. Even the

¹⁹ Lydia Howland is the youngest daughter of Alize Howland and she is a theatre actress and chooses the unconventional path for her career. She is the one, who truly understands her mother's condition and manages to connect with her.

²⁰ Genova, L., *Still Alice*, 2007, p. 181.

²¹ Genova, L., *Still Alice*, 2007, p. 191.

²² Genova, L., *Still Alice*, 2007, p. 203.

well-intentioned and educated people keep a fearful distance from the mentally unstable, treated them like an outcast. In *Madness and Civilization: The History of Insanity in the Age of Reason*, Foucault examines the historical shift from lepers to madmen as marginalized members of society, demonstrating an enduring societal inclination to delineate, classify, and ostracize specific individuals. He expands the concept of confinement to include not just physical facilities like the Panopticon model of the Hospital General in Paris (1656), but also larger social and economic mechanisms that exclude specific individuals and behaviors. Foucault maintains that lunacy is a product of societal and intellectual influences, which exert control and shape its manifestation. Consequently, individuals who are perceived as mentally unstable are often marginalized and disregarded. To comprehend mental instability, one must acknowledge it as a medical condition as well as a socio-political concern. Foucault posits that art and literature provide opportunities for lunacy to confront cultural norms and compel responses to unsettling inquiries, therefore interrogating the ethical framework employed by psychiatrists and psychologists. This viewpoint challenges the way society portrays and handles mental illness and cognitive disability [20].

The following lines are the reflection of Alice's inner-self. The term "expansive grandeur that was Harvard" paints a striking picture of the prominent university, highlighting its size and magnificence. This imagery contrasts with Alice's subsequent portrayal of boredom, ignorance, and alienation, emphasizing the sharp contrast between her outward appearance and her inner reality. Alice's comparison of her cognitive psychology career to her "broken cognitive psyche" is metaphorical. It depicts Alice's struggle with Alzheimer's illness by comparing her mental state to the subject matter she teaches. This figurative phrase enhances the description of Alice's inner struggle. The term "there was not a room for" personifies Harvard, associating it with the ability to apportion space. This personification underlines the university's apparent lack of accommodation for Alice's illness, exacerbating her sense of loneliness in the academic setting.

Alice felt bored, ignored, and alienated in her office. In the expansive grandeur that was Harvard, there was not a room for a cognitive psychology professor with a broken cognitive psyche.²³

She found nothing meaningful around her, so she slept most of the time. She developed a disturbing lack of confidence in her knowledge, could not be sure that the woman sitting across her was her daughter? Her past was getting unhinged from her present. Information processing ability was profoundly affected. She could not make out what was being talked? Who was talking about what? She could not recognize Lydia. Auditory and visual hallucinations are another impact of Alzheimer. Patient can see and feel things around her; completely delusional; can hear people talk with nobody around; can see people in front of them with nobody around. They believe in whatever they see and hear. It is the people and care givers around an Alzheimer patient that have more challenging task while dealing with an AD patient. Alice was gifted a video memoir in the form of three digital versatile discs (DVD's) by Lydia. It was full of their childhood memories, wedding & dating with John. She remembered everything correctly but amused by the way everyone remembered them differently. As they emphasized more on their own perspectives.

Even biographies / realities not saturated with disease are vulnerable to holes and distortions.²⁴

XV. RECLAIMING SELFHOOD

Alice desperately wanted some sort of connection, wanted to inhabit a place that would belong to her. She goggled out the people names with early onset of Alzheimer. She needed her new world, a world of dementia; she could not be alone in it. There should be other people who were suffering from this demon at an early age; she needed to find out urgently. There was no support group for Alzheimer patients; support groups were for the caregivers of Alzheimer patients. (They would not be considered capable to participate in the forum) She somehow with the help of a social worker got the contact number of three early onsets of Alzheimer patients, Mary, Cathy, and Dan. She was excited like a child; could not wait to meet them; tried to know how they have been coming up with this illness? She was trying to find solace in the collective sense of grief, a shared sense of suffering.

Alice invited Mary, Cathy, and Dan over her place. They instantly connected, they laughed over their eccentricities; they nodded, laughed and cried over stories of lost keys, lost thoughts, lost ways, lost words, and lost life dreams. They shared stories of their earliest symptoms, their struggle to get a correct diagnosis, their strategies for coping, and living with the demon. Alice felt unedited and truly heard. She felt normal.²⁵

Dementia Advocacy and Support Network International (DASNI) and Alzheimer's Association gave her an opportunity to once again speak in front of audience and share her own experiences of dealing with Alzheimer's Disease and to speak to the world on the behalf of all people dealing with AD. Alice prepared her speech and holding the butterfly necklace in her hand, she delivered it without faltering or forgetting.

²³ Genova, L., *Still Alice*, 2007, p. 222.

²⁴ Genova, L., *Still Alice*, 2007, p. 229.

²⁵ Genova, L., *Still Alice*, 2007, p. 249.

I am Alice having an early onset of Alzheimer's Disease. I am not incompetent: it's just that I do not comprehend texts, and conversations. I am not without language and opinions: it's just that words seem to float away from me: I am neither here nor there, some time here and sometimes there like Dr. Seuss in a bizarre land. I stay at a very lonely place, no longer read and write, no books, no research articles. My reality is distorted, my thinking, analytical abilities gummed up by Amyloid -Beta. I can't judge spatial distances, So, I drop things and falls a lot. My short- memory is hanging on by a couple of frayed threads. I am losing my yesterdays; my present is gummed up, my future bleak. I fear tomorrow that I will no longer be me; Is my identity can transcend neurons, proteins, defective DNA? Is my soul and spirit immune to the ravages of AD. Being diagnoses with AD is like being branded with a scarlet A. I am not just what I say or do or remember: I am more than that. I am a wife, a mother, to be grandmother, a human being. I still feel, understand and worthy of the love and joy. Please look us in the eye, talk directly to us. Don't panic when we make mistakes. My brain no longer works, but I use my ears for unconditional listening, offer my shoulder to cry on and my arms are for hugging others with dementia. I am not dying but I am going to live with Alzheimer's Disease. I encourage you to power us not limit us.²⁶

XVI. CONCLUSION

The novel conveys a poignant message and urges society to listen to individuals with cognitive disabilities and recognize that their silence doesn't equate to a lack of thoughts or feelings. It encourages engagement with their silence to understand their perspective, emphasizing the importance of inclusivity and sensitivity in interactions with them. People with Alzheimer's face a relentless progression of symptoms, including the loss of familiar memories and the erosion of free will and agency. Loneliness and alienation are common struggles for those with Alzheimer's, highlighting the importance of awareness to reduce stigma. Despite the challenges posed by the disease, there remains a sanctuary within the brain that provides emotional support. The text employs a narrative perspective centered on Alice's point of view, situated within familiar familial and social contexts. This approach ensures that Alice is consistently recognized and empathized with by the reader, even as her illness progresses. By intimately portraying Alice's emotional, physical, and intellectual experiences, the reader is compelled to continually reconstruct her identity, maintaining her dynamic essence as still Alice. The novel delves into the intricate dynamics of self-hood and agency within the context of Alzheimer's disease. It suggests that agency is a nuanced concept, seemingly offering choices yet ultimately constrained. The narrative is situated at the intersection of absence and presence, exploring the complexities of navigating identity and autonomy in the face of cognitive decline.

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